2015

South Australia: patient outcomes in palliative care: July - December 2014

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Abstract

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this PCOC report, data submitted for the July to December 2014 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

Keywords

PCOC, july, australia, south, 2014, care, december, palliative, outcomes, patient

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PCOC

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outcomes collaboration

South Australia

Patient Outcomes in Palliative Care

July – December 2014

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www.pcoc.org.au

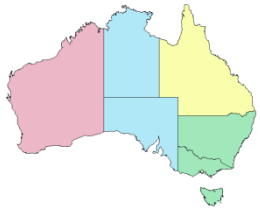
About the Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care for all Australians*. This is achieved via the PCOC dataset; a multi-purpose framework designed to:

- provide clinicians with an approach to systematically assess individual patient experiences,
- define a common clinical language to streamline communication between palliative care providers and
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

The PCOC dataset includes the clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

PCOC has divided Australia into four zones for the purpose of engaging with palliative care service providers. Each zone is represented by a chief investigator from one of the collaborative centres. The four PCOC zones and their respective chief investigators are:



Central Zone	**Professor Kathy Eagar**, Australian Health Services Research Institute, University of Wollongong
North Zone	**Professor Patsy Yates**, Institute of Health and Biomedical Innovation, Queensland University of Technology
South Zone	**Professor David Currow**, Department of Palliative and Supportive Services, Flinders University
West Zone	**Dr Claire Johnson**, Cancer and Palliative Care Research and Evaluation Unit, University of WA

Each zone is also represented by one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement. The national team, located within the Australian Health Services Research Institute at the University of Wollongong, coordinates the patient outcomes reporting, education program, and quality activities across the four zones.

If you would like more information or have any queries about this report please contact your local quality improvement facilitator or contact the national office at pcoc@uow.edu.au or phone (02) 4221 4411.

PCOC palliative care outcomes collaboration

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this PCOC report, data submitted for the July to December 2014 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

Patient outcomes are reported for a total of 18,310 patients, with 23,449 episodes of care and 53,467 palliative care phases. The information included in this report is determined by a data scoping method. See Appendix A for more information on the data included in this report.

Throughout this report, patient information for South Australia is presented alongside the national figures for comparative purposes. The national figures are based on information submitted by 95 services, of which:

- 53 are inpatient services. Inpatient services include patients who have been seen in designated palliative care beds as well as non-designated bed consultations.
- 27 are community services. These services include primarily patients seen in the community as well as some patients with ambulatory/clinic episodes.
- 15 are services with both inpatient and community settings.

A full list of the services included in the national figures can be found at www.pcoc.org.au.

The South Australian figures in this report are based on information submitted by 13 services. A list of these services is presented in Table 1 on the following page.

Interpretation hint:

Some tables throughout this report may be incomplete. This is because some items may not be applicable to South Australia or it may be due to data quality issues.

Please use the following key when interpreting the tables:

na **The item is not applicable.**
u **The item was unavailable.**
s **The item was suppressed due to insufficient data as there was less than 10 observations.**

Table 1 List of South Australian services included in this report

Service name	Setting of care
Adelaide Hills Community Health Service	Community
Calvary Health Care Adelaide (Mary Potter Hospice)	Inpatient
Inner North Palliative Care	Community
Murray Mallee	Community
Northern Adelaide Palliative Service	Both inpatient and community
Port Pirie Regional Health Service	Community
Riverland Palliative Care Service	Community
South Coast Palliative Care Service	Community
South East Regional Community Health Service	Community
Southern Adelaide Palliative Care Consult	Inpatient
Southern Adelaide Palliative Services	Both inpatient and community
Whyalla Palliative Care Service	Both inpatient and community
Yorke Peninsula Palliative Care	Community

Section 1 Benchmark summary

1.1 South Australia at a glance

Table 2 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			SA Score	Benchmark Met?	SA Score	Benchmark Met?
1. Time from ready for care to episode start	Benchmark 1: Patients episode commences on the day of, or the day after date ready for care	90%	91.3	Yes	88.8	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	87.4	No	82.4	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	87.8	No	81.9	No
	Benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	44.4	No	53.0	No
	Benchmark 3.3: SAS Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end	90%	83.8	No	78.7	No
	Benchmark 3.4: SAS Patients with moderate/severe distress from pain at phase start, with absent/mild at phase end	60%	46.5	No	42.8	No

Table 3 Summary of outcome measure 4: Average improvement on the 2014 baseline national average (X-CAS)

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	-0.09	No
	Benchmark 4.2: Other symptoms	-0.06	No
	Benchmark 4.3: Family/carer	-0.07	No
	Benchmark 4.4: Psychological/spiritual	-0.03	No
SAS	Benchmark 4.5: Pain	-0.32	No
	Benchmark 4.6: Nausea	-0.05	No
	Benchmark 4.7: Breathing problems	-0.10	No
	Benchmark 4.8: Bowel problems	-0.24	No

The benchmark for outcome measure 4 is zero.

For more information on the outcome measures and benchmarks, see Section 2.

1.2 National benchmark profiles

In this section, the national profiles for selected benchmarks are split by setting (inpatient or community) and presented graphically.

The selected benchmarks included are:

- Benchmark 1 Patients episode commences on the day of or the day after date ready for care
- Benchmark 2 Patients in the unstable phase for 3 days or less
- Benchmark 3.1 PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end
- Benchmark 3.2 PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end
- Benchmark 3.3 SAS: Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end
- Benchmark 3.4 SAS: Patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end

Interpretation hint:

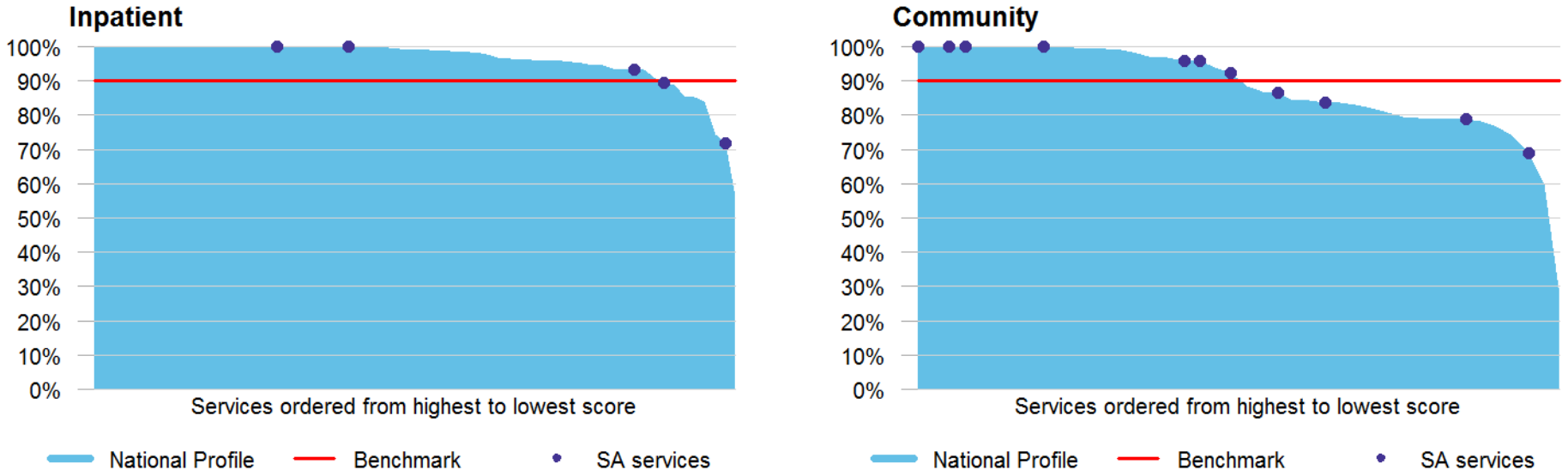
The national profile graphs on the following pages allow services to see how they are performing in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. South Australian services are highlighted as dots on the graph.

If no dot is present on a particular graph, this means that South Australian services have not met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or not having any data falling into a particular category, for example, no phases starting with moderate/severe SAS pain.

The red line on the graph indicates the benchmark for that outcome measure.

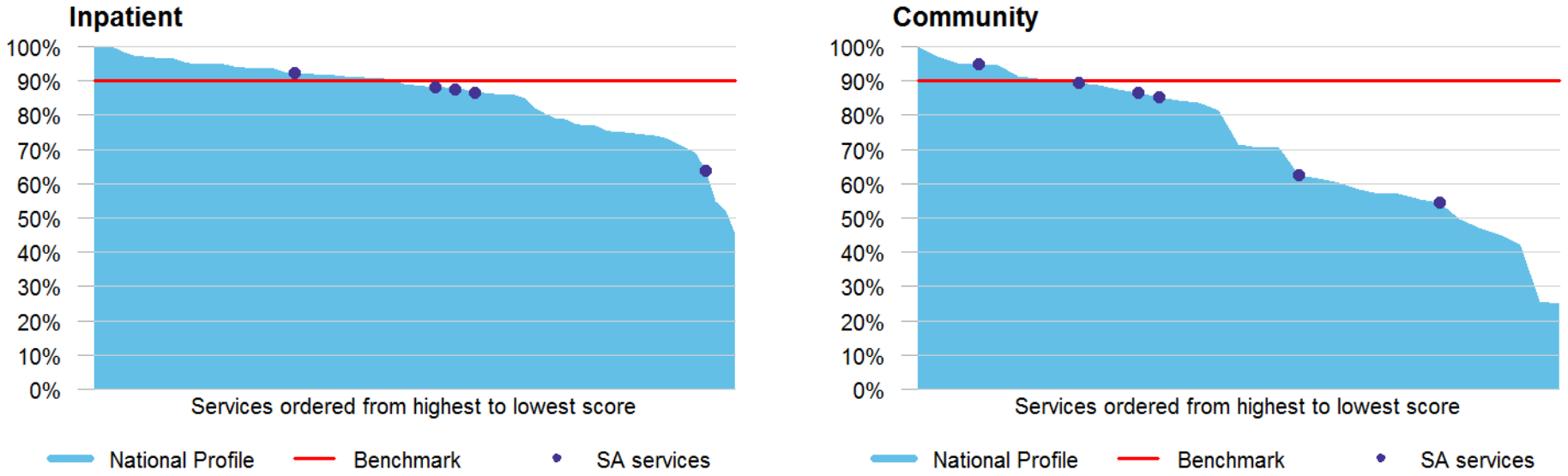
Outcome measure 1 – Time from date ready for care to episode start

Figure 1 Percentage of patients with episodes started on the day of, or the day after date ready for care



Outcome measure 2 – Time in unstable phase

Figure 2 Percentage of patients in the unstable phase for 3 days or less



Outcome measure 3 – Change in pain

Figure 3 PCPSS: Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end

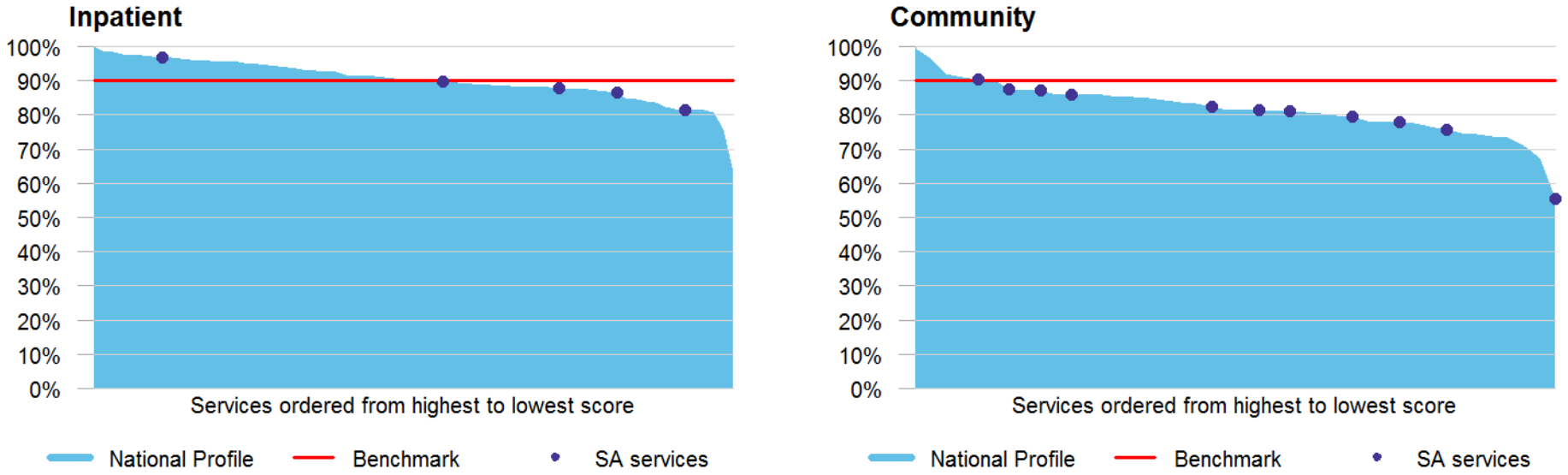


Figure 4 PCPSS: Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end

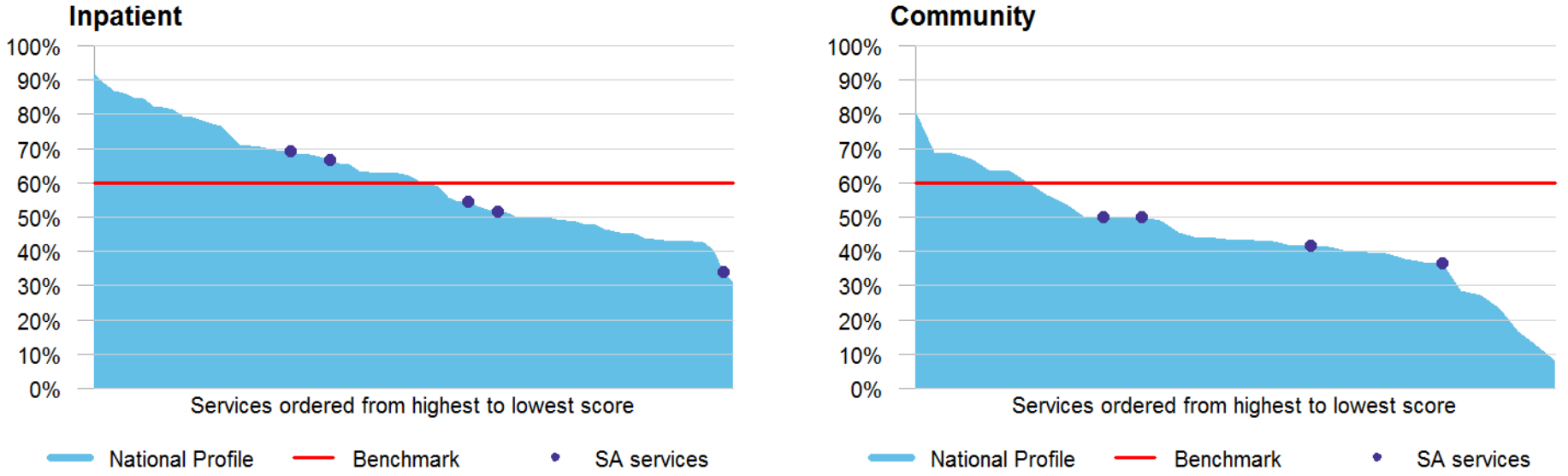


Figure 5 SAS: Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end

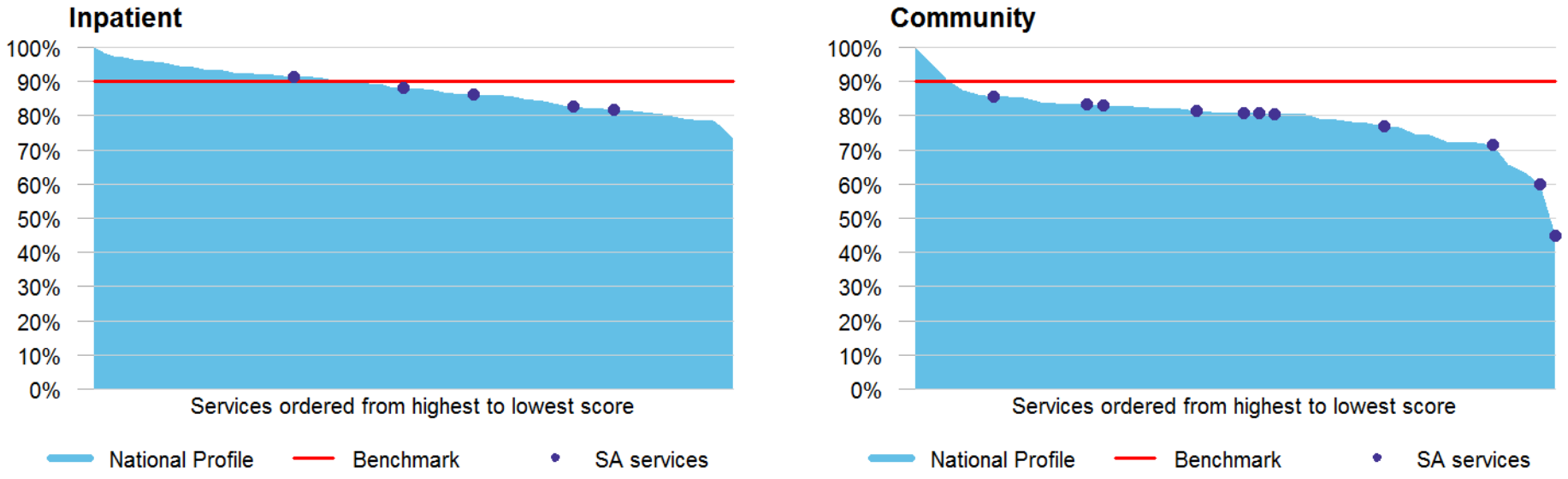
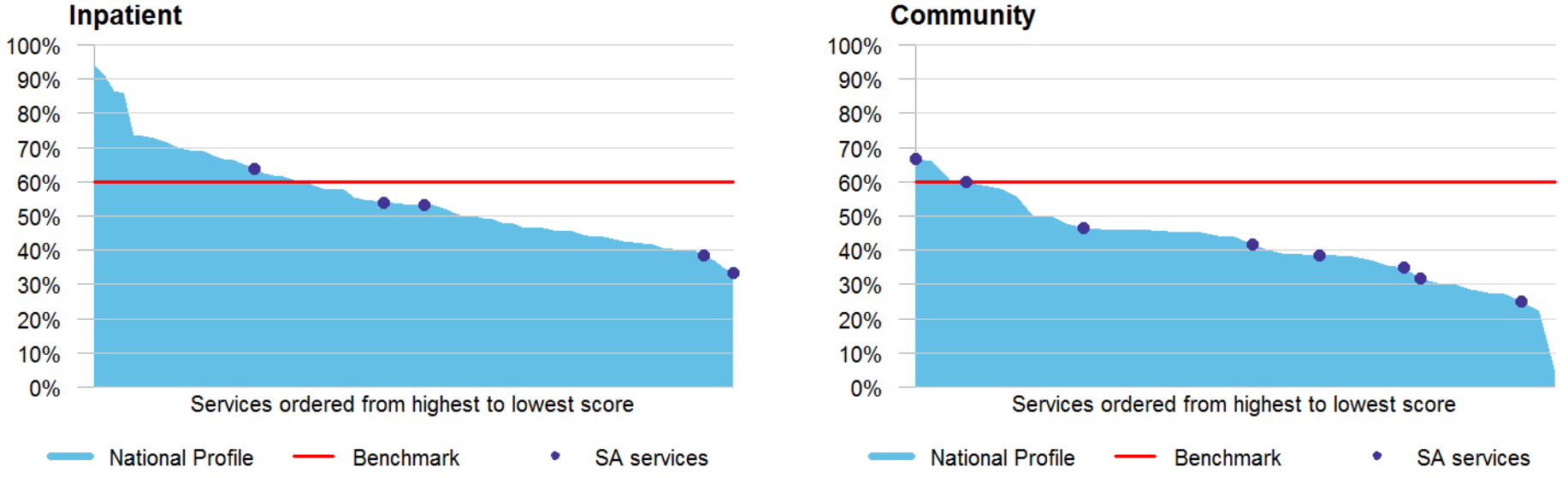


Figure 6 SAS: Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end



Section 2 Outcome measures in detail

2.1 Outcome measure 1 – Time from date ready for care to episode start

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (all services are being benchmarked together).

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following date ready for care.

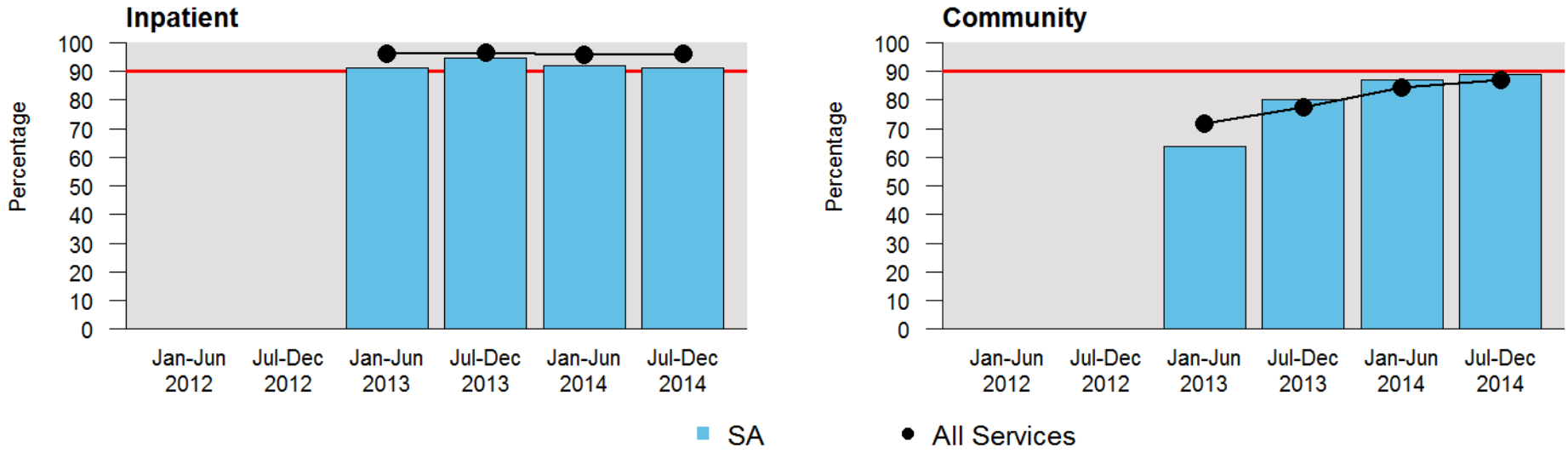
Table 4 Time from date ready for care to episode start by setting

Time (in days)	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Same day	670	84.4	10,032	89.5	698	83.2	8,240	82.2
Following day	55	6.9	768	6.8	47	5.6	493	4.9
2-7 days	60	7.6	380	3.4	58	6.9	953	9.5
8-14 days	5	0.6	22	0.2	16	1.9	203	2.0
Greater than 14 days	4	0.5	12	0.1	20	2.4	140	1.4
Average	1.4	na	1.1	na	2.4	na	1.9	na
Median	1	na	1	na	1	na	1	na

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Interpretation hint:
Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.

Figure 7 Percentage of episodes that met outcome measure 1 over time



2.2 Outcome measure 2 – Time in unstable phase

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and/or
- a patient experiences a rapid increase in the severity of an existing problem, and/or
- a patient's family/carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

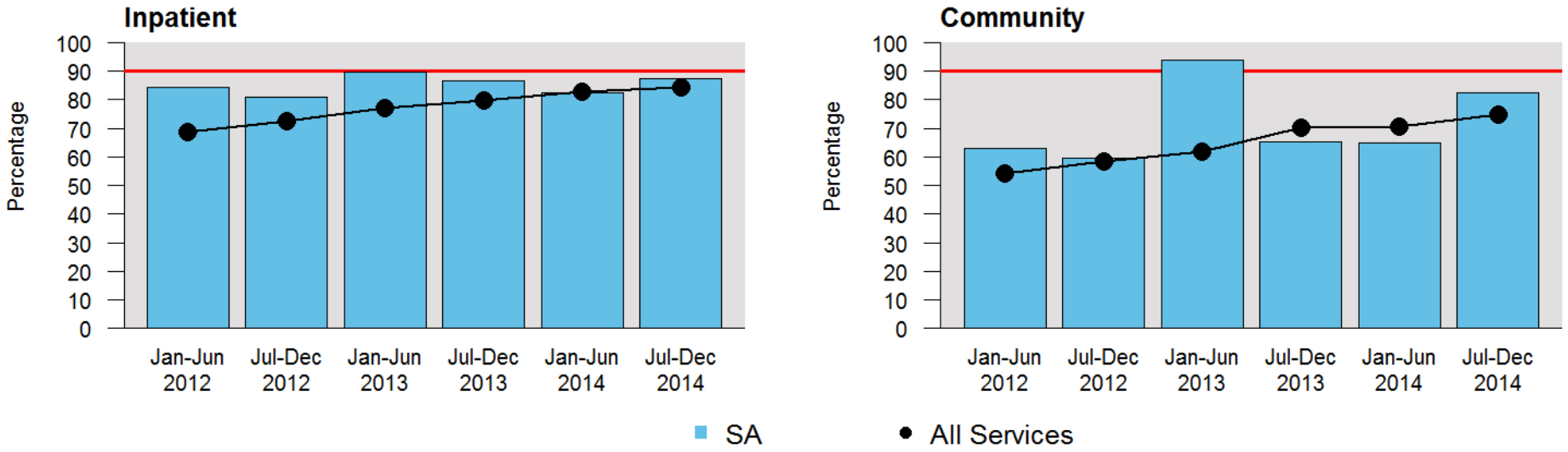
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom/crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

Benchmark 2: This benchmark relates to time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for 3 days or less.

Table 5 Time in unstable phase by setting

Length of unstable phase	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Same day	9	3.6	208	3.2	39	24.5	733	23.1
1 day	117	47.4	2,917	44.6	57	35.8	1,078	33.9
2 days	65	26.3	1,611	24.6	24	15.1	362	11.4
3 days	25	10.1	776	11.9	11	6.9	208	6.5
4-5 days	15	6.1	626	9.6	5	3.1	220	6.9
6-7 days	8	3.2	225	3.4	5	3.1	175	5.5
8-14 days	6	2.4	143	2.2	6	3.8	171	5.4
Greater than 14 days	2	0.8	38	0.6	12	7.5	233	7.3
Total	***247***	***100.0***	***6,544***	***100.0***	***159***	***100.0***	***3,180***	***100.0***

Figure 8 Percentage of phases that met benchmark 2 over time



2.3 Outcome measure 3 – Change in pain

Pain management is acknowledged as a core business of palliative care services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain. The PCPSS is clinician rated and measures the severity of pain as a clinical problem while the SAS is patient rated and measures distress caused by pain.

There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to be included in the benchmarks.

Scores for PCPSS
0 absent
1 mild
2 moderate
3 severe

Scores for SAS
0 absent
1-3 mild
4-7 moderate
8-10 severe

Interpretation hint:

This outcome measure should be viewed in conjunction with Table 29 to Table 32 and Appendix B.

Benchmarks 3.1 and 3.3: These benchmarks relates to patients who have absent or mild pain at the start of their phase of palliative care. To meet these benchmarks, 90% of phases must end with the patient still experiencing only absent or mild pain.

Benchmarks 3.2 and 3.4: These benchmarks relates to patients who have moderate or severe pain at the start of their phase of palliative care. To meet these benchmarks, 60% of phases must end with the patient's pain reduced to being absent or mild.

Table 6 Summary of outcome measure 3

Benchmark	Inpatient				Community			
	SA		All Services		SA		All Services	
	N*	%	N*	%	N*	%	N*	%
Benchmark 3.1: PCPSS	723	87.8	15,589	90.9	618	81.9	14,943	84.8
Benchmark 3.2: PCPSS	304	44.4	5,346	57.1	166	53.0	3,933	50.1
Benchmark 3.3: SAS	569	83.8	13,526	88.1	526	78.7	13,991	82.7
Benchmark 3.4: SAS	325	46.5	6,541	52.8	243	42.8	4,879	45.4

*Total number of phases included in this benchmark.

Figure 9 Trends in benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

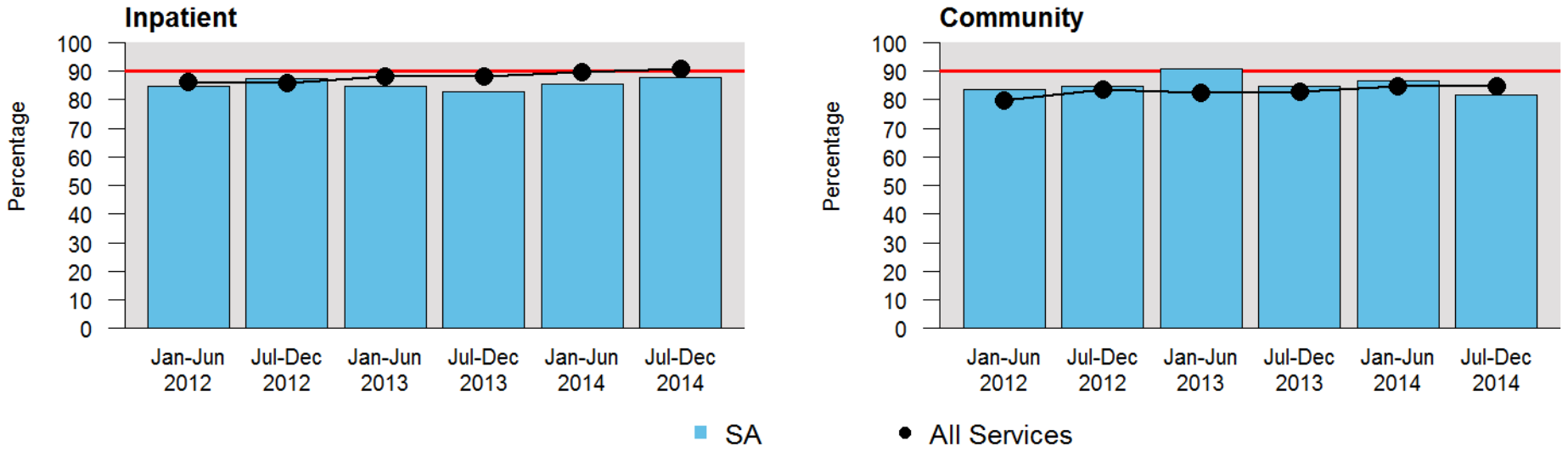


Figure 10 Trends in benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild at phase end by setting

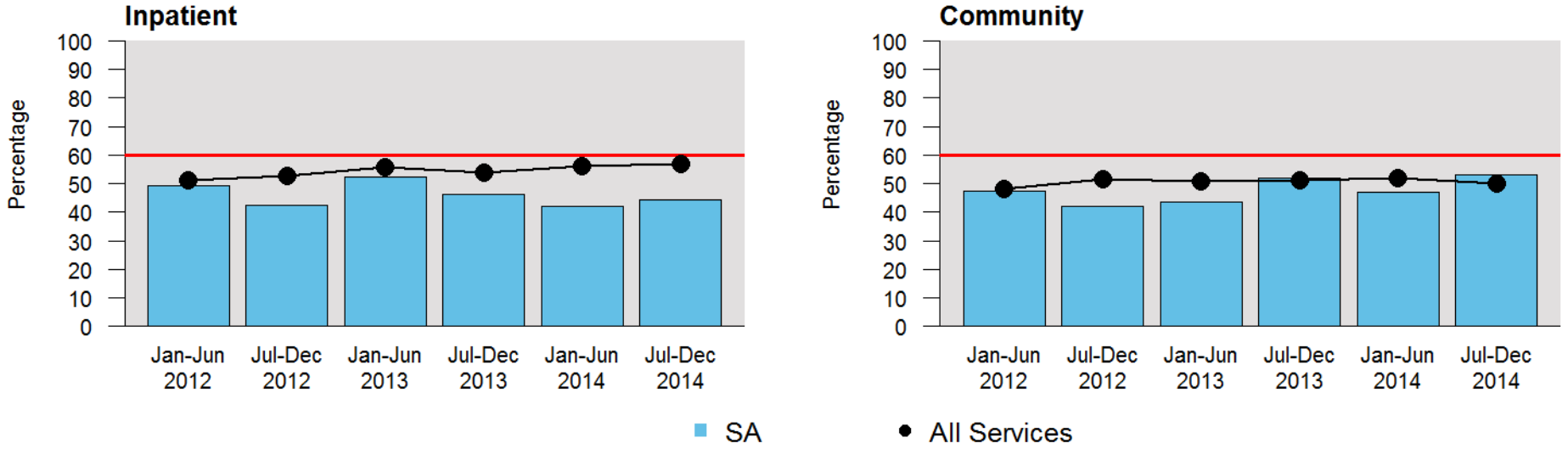


Figure 11 Trends in benchmark 3.3: SAS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

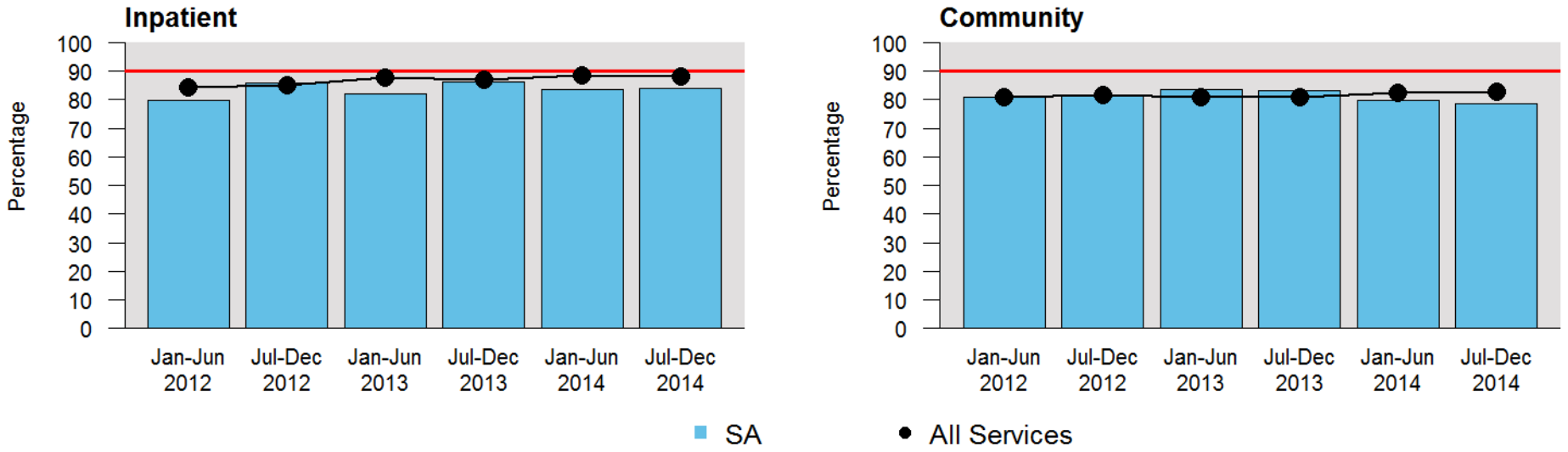
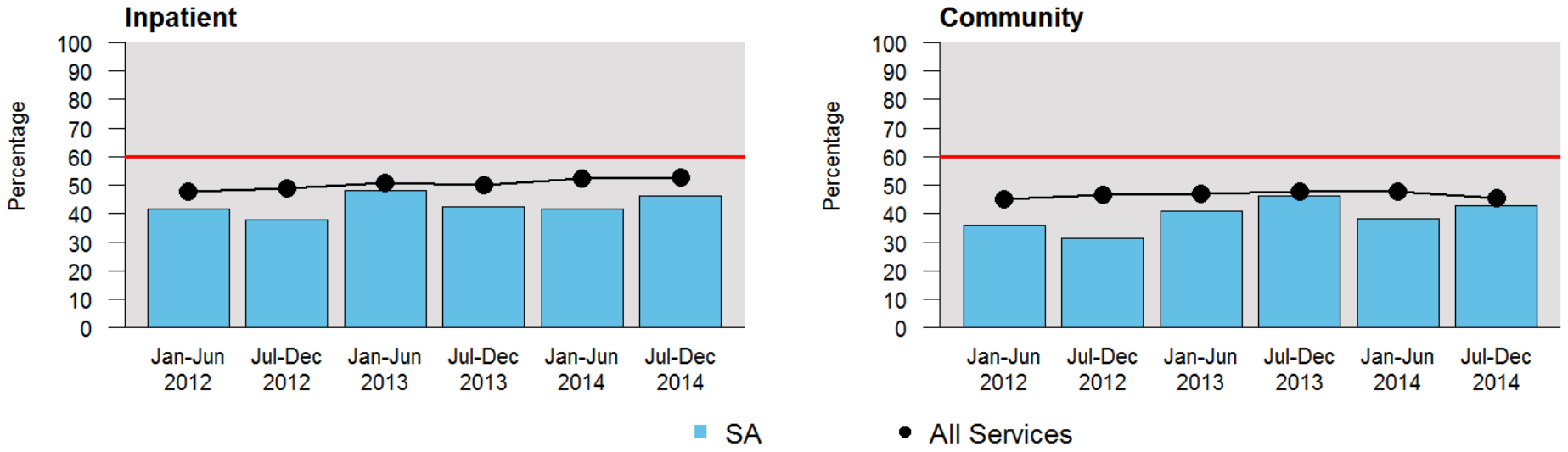


Figure 12 Trends in benchmark 3.4: SAS Patients with moderate/severe pain at phase start, with absent/mild at phase end by setting



2.4 Outcome measure 4 – Change in symptoms relative to the baseline national average (X-CAS)

Outcome measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included in this report and the baseline reference period is January to June 2014. The suite of benchmarks included in outcome measure 4 are generally referred to as X-CAS – *CAS* standing for *Case-mix Adjusted Score*, and the *X* to represent that multiple symptoms are included. As X-CAS looks at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change).

Table 7 Summary of outcome measure 4

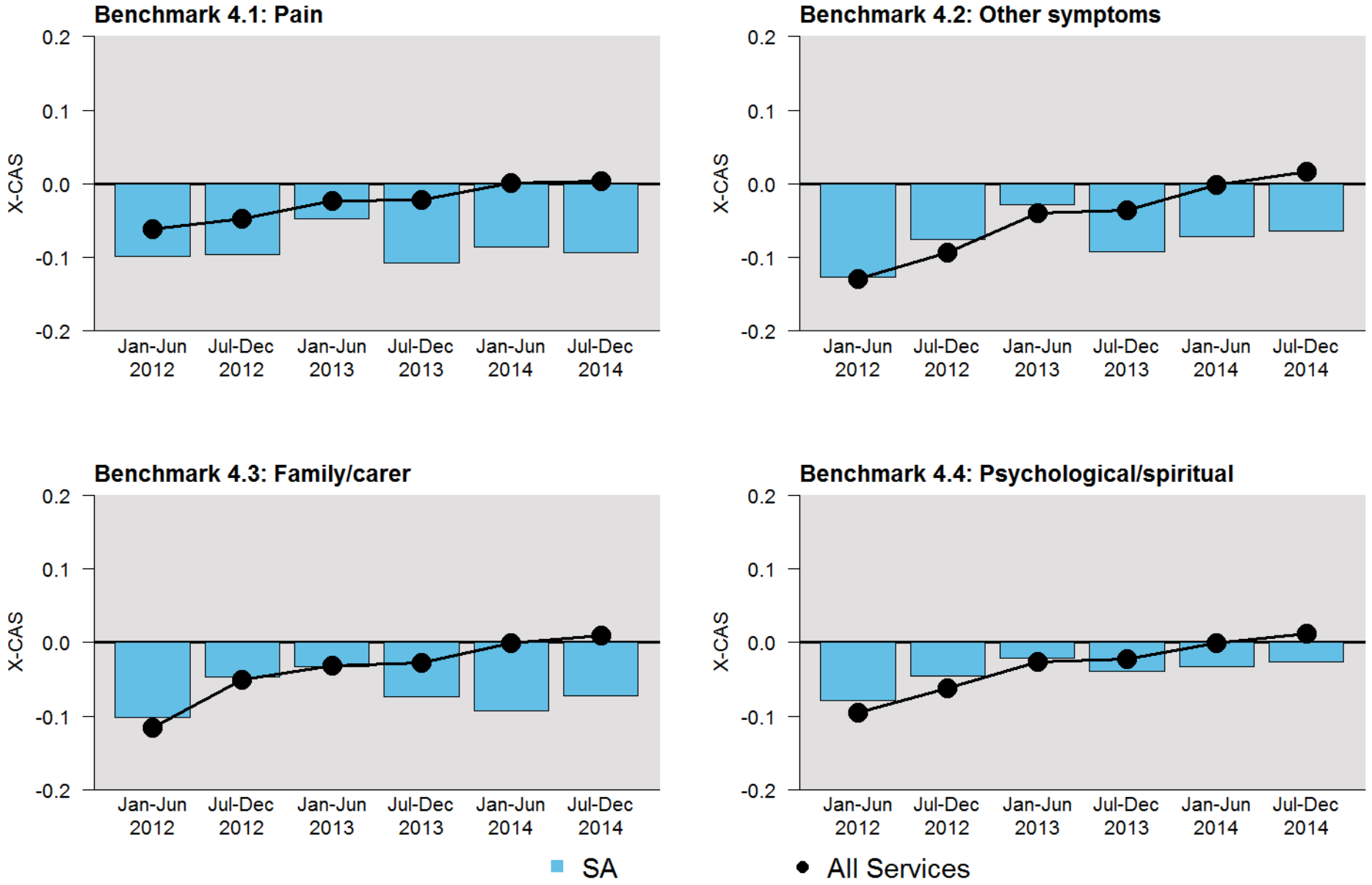
Benchmark: Symptom	SA				All Services			
	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
4.1: PCPSS Pain	-0.09	1,811	960	53.0	0.00	39,811	23,009	57.8
4.2: Other symptoms	-0.06	1,817	1,062	58.4	0.02	39,616	24,870	62.8
4.3: Family/carer	-0.07	1,755	989	56.4	0.01	39,198	23,943	61.1
4.4: Psychological/spiritual	-0.03	1,814	919	50.7	0.01	40,087	20,819	51.9
4.5: SAS Pain	-0.32	1,663	895	53.8	-0.01	38,937	23,873	61.3
4.6: Nausea	-0.05	1,663	1,320	79.4	0.02	38,580	31,707	82.2
4.7: Breathing Problems	-0.10	1,659	1,101	66.4	0.02	38,415	26,699	69.5
4.8: Bowel Problems	-0.24	1,660	1,035	62.3	0.03	38,024	27,132	71.4

Interpretation hint:

The X-CAS measures are calculated relative to a baseline reference period, which has been updated for this report and is now the period January to June 2014. As a result:

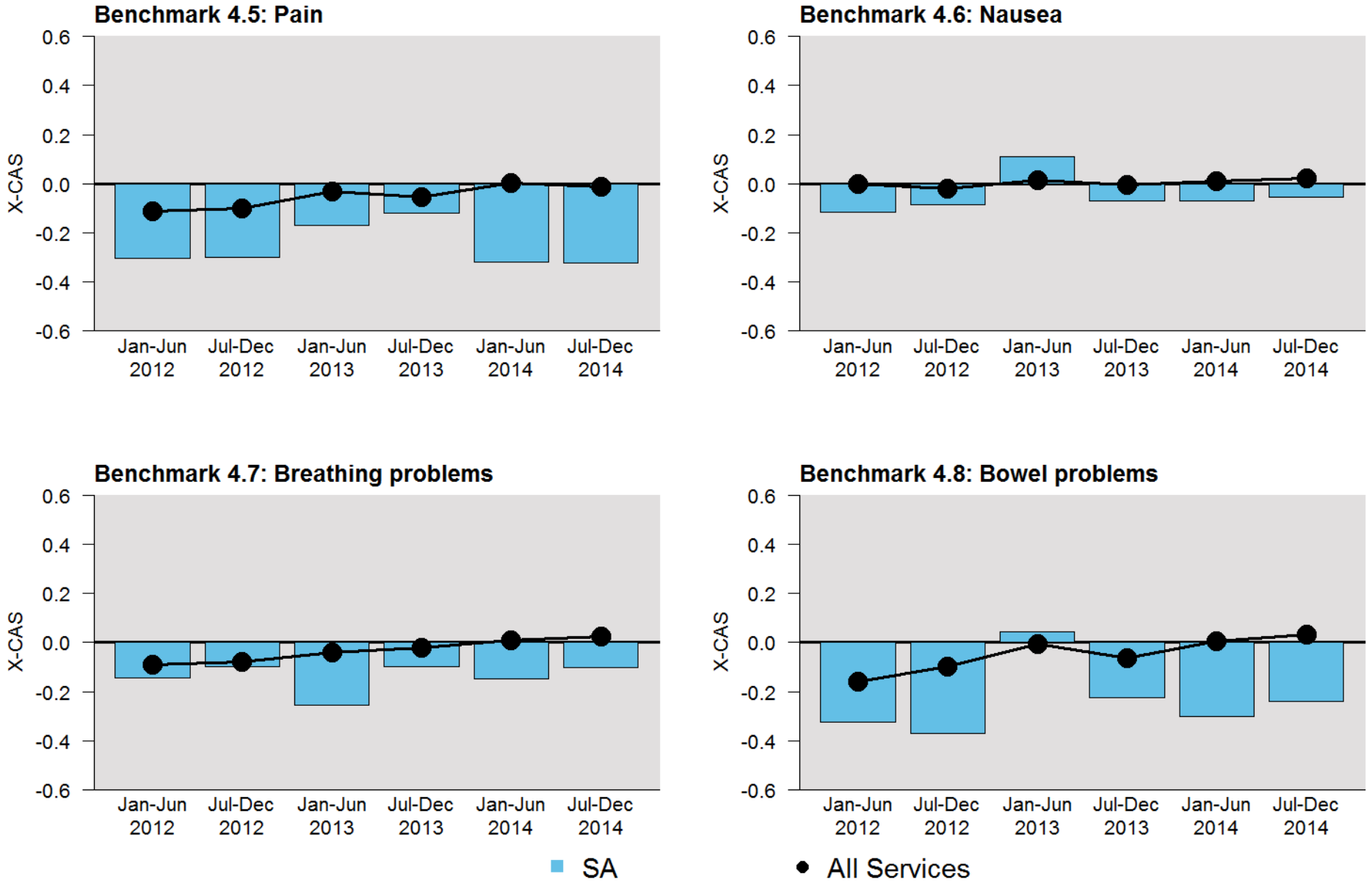
If X-CAS for SA is greater than 0 then on average, your patients' change in symptom was better than similar patients in the baseline reference period.
If X-CAS for SA is equal to 0 then on average, your patients' change in symptom was about the same as similar patients in the baseline reference period.
If X-CAS for SA is less than 0 then on average, your patients' change in symptom was worse than similar patients in the baseline reference period.

Figure 13 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Figure 14 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Section 3 Descriptive analysis

This section provides descriptive information of the data submitted by South Australian services at each of the three levels – patient, episode and phase.

Patient level information describes demographics such as Indigenous status, sex, preferred language and country of birth. This information about the patient provides a context to the episode and phase level information and enhances the meaningfulness of patient outcomes.

Episode level information describes the setting of palliative care service provision. It also includes information relating to the facility/organisation that has referred the patient, how an episode starts/ends and the setting in which the patient died.

Phase level information describes the clinical condition of the patient during the episode, using five clinical assessment tools. These are phase of illness, the patient's functional status and performance, pain and other common symptoms, the patient's psychological/spiritual and family/carer domain.

Summaries of the national data are included for comparative purposes.

3.1 Profile of palliative care patients

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family/carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 8 shows the Indigenous status for all the patients in South Australia and nationally.

Table 8 Indigenous status

Indigenous status	SA		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	11	0.8	179	1.0
Torres Strait Islander but not Aboriginal origin	1	0.1	13	0.1
Both Aboriginal and Torres Strait Islander origin	0	0.0	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	1,235	94.1	17,739	96.9
Not stated/inadequately described	66	5.0	366	2.0
Total	***1,313***	***100.0***	***18,310***	***100.0***

Table 9 shows the breakdown of deaths for all patients in South Australia and nationally for the reporting period. All inpatient deaths are reported in the hospital category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 9 Place of death

Place of death	SA		All Services	
	N	%	N	%
Private residence	158	22.8	1,834	20.2
Residential aged care facility	40	5.8	647	7.1
Hospital	493	71.0	6,507	71.7
Not stated/inadequately described	3	0.4	88	1.0
Total	***694***	***100.0***	***9,076***	***100.0***

The following two tables show the country of birth and the preferred language respectively for all patients in South Australia and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 10 is in descending order of the most frequent country of birth according to the 2006 Census (e.g. Italy was the fifth most common country of birth in the 2006 Census). The same approach has been taken with Table 11 (e.g. Greek was the third most frequently spoken language in the 2006 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 10 Country of birth

Country of birth	SA		All Services	
	N	%	N	%
Australia	910	69.3	11,458	62.6
England	144	11.0	1,410	7.7
New Zealand	5	0.4	363	2.0
China	3	0.2	170	0.9
Italy	33	2.5	679	3.7
Vietnam	4	0.3	138	0.8
India	3	0.2	139	0.8
Scotland	14	1.1	280	1.5
Philippines	3	0.2	76	0.4
Greece	18	1.4	390	2.1
Germany	18	1.4	233	1.3
South Africa	7	0.5	91	0.5
Malaysia	0	0.0	68	0.4
Netherlands	13	1.0	194	1.1
Lebanon	1	0.1	86	0.5
All other countries	64	4.9	2,270	12.4
Not stated/inadequately described	73	5.6	265	1.4
Total	***1,313***	***100.0***	***18,310***	***100.0***

Table 11 Preferred language

Preferred language	SA		All Services	
	N	%	N	%
English	1,210	92.2	16,528	90.3
Italian	14	1.1	335	1.8
Greek	9	0.7	280	1.5
Chinese[(a)]	2	0.2	147	0.8
Arabic[(b)]	0	0.0	100	0.5
Vietnamese[(c)]	3	0.2	60	0.3
Spanish / Portuguese[(d)]	0	0.0	35	0.2
Filipino / Indonesian[(e)]	0	0.0	19	0.1
German[(f)]	3	0.2	31	0.2
Hindi[(g)]	0	0.0	22	0.1
Croatian / Macedonian[(h)]	3	0.2	116	0.6
Korean	0	0.0	16	0.1
Turkish[(i)]	0	0.0	32	0.2
Polish[(j)]	2	0.2	30	0.2
Maltese	0	0.0	35	0.2
All other languages	67	5.1	519	2.8
Not stated/inadequately described	0	0.0	5	0.0
Total	***1,313***	***100.0***	***18,310***	***100.0***

(a) Chinese includes: Cantonese, Hakka, Mandarin, Wu and Min Nan; **(b) Middle Eastern Semitic Languages includes:** Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, Mandaean (Mandaic); **(c) Mon-Khmer includes:** Khmer, Mon; **(d) Iberian Romance includes:** Catalan; **(e) Southeast Asian Austronesian Languages includes**: Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo (Hiligaynon), Javanese, Pampangan; **(f) German and Related Languages include:** Letzeburgish, Yiddish; **(g) Indo-Aryan includes:** Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, Fijian Hindustani; **(h) South Slavic includes:** Bosnian, Bulgarian, Serbian, Slovene; **(i) Turkic includes:** Azeri, Tatar, Turkmen, Uygur, Uzbek; **(j) West Slavic includes:** Czech, Slovak

Table 12 and Table 13 present a breakdown of malignant and non-malignant diagnosis for the patients seen by South Australian services and at the national level. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 0 (0.0%) patients in South Australia and was not stated for 58 (0.3%) patients nationally.

Table 12 Primary diagnosis - malignant

Primary diagnosis	SA			All Services		
	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	20	1.8	1.5	220	1.6	1.2
Breast	68	6.2	5.2	1,116	7.9	6.1
CNS	26	2.4	2.0	281	2.0	1.5
Colorectal	133	12.2	10.1	1,610	11.4	8.8
Other GIT	100	9.1	7.6	1,406	10.0	7.7
Haematological	75	6.9	5.7	837	6.0	4.6
Head and neck	56	5.1	4.3	784	5.6	4.3
Lung	262	23.9	20.0	3,083	21.9	16.8
Pancreas	81	7.4	6.2	898	6.4	4.9
Prostate	75	6.9	5.7	960	6.8	5.2
Other urological	38	3.5	2.9	592	4.2	3.2
Gynaecological	44	4.0	3.4	707	5.0	3.9
Skin	33	3.0	2.5	528	3.8	2.9
Unknown primary	28	2.6	2.1	404	2.9	2.2
Other primary malignancy	42	3.8	3.2	494	3.5	2.7
Malignant – not further defined	13	1.2	1.0	143	1.0	0.8
All malignant	***1,094***	***100.0***	***83.3***	***14,063***	***100.0***	***76.8***

Table 13 Primary diagnosis - non-malignant

Primary diagnosis	SA			All Services		
	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	40	18.3	3.0	818	19.5	4.5
HIV/AIDS	1	0.5	0.1	12	0.3	0.1
End stage kidney disease	20	9.1	1.5	418	10.0	2.3
Stroke	8	3.7	0.6	223	5.3	1.2
Motor neurone disease	17	7.8	1.3	165	3.9	0.9
Alzheimer's dementia	11	5.0	0.8	157	3.7	0.9
Other dementia	8	3.7	0.6	242	5.8	1.3
Other neurological disease	14	6.4	1.1	355	8.5	1.9
Respiratory failure	39	17.8	3.0	749	17.9	4.1
End stage liver disease	12	5.5	0.9	159	3.8	0.9
Diabetes and its complications	1	0.5	0.1	19	0.5	0.1
Sepsis	6	2.7	0.5	94	2.2	0.5
Multiple organ failure	4	1.8	0.3	104	2.5	0.6
Other non-malignancy	29	13.2	2.2	582	13.9	3.2
Non-malignant – not further defined	9	4.1	0.7	92	2.2	0.5
All non-malignant	***219***	***100.0***	***16.7***	***4,189***	***100.0***	***22.9***

3.2 Profile of palliative care episodes

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as an inpatient or community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to inpatient) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 14 below presents the number and percentage of episodes by age group and sex for the patients seen by South Australian services and at the national level. Age has been calculated as at the beginning of each episode.

Table 14 Age group by sex

Age group	SA				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	3	0.3	0	0.0	31	0.2	28	0.3
15 - 24	2	0.2	0	0.0	42	0.3	42	0.4
25 - 34	3	0.3	5	0.6	90	0.7	103	0.9
35 - 44	8	0.9	20	2.5	279	2.2	398	3.6
45 - 54	63	6.8	65	8.2	767	6.2	943	8.5
55 - 64	148	16.0	124	15.6	1,913	15.4	1,748	15.8
65 - 74	269	29.1	209	26.3	3,374	27.2	2,491	22.6
75 - 84	281	30.4	232	29.2	3,793	30.5	2,868	26.0
85+	147	15.9	140	17.6	2,128	17.1	2,411	21.9
Not stated/inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
Total	***924***	***100.0***	***795***	***100.0***	***12,417***	***100.0***	***11,032***	***100.0***

Note: Records where sex was not stated or inadequately described are excluded from the table.

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 15 presents referral source by setting.

Table 15 Referral source by setting

Referral source	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Public hospital	400	48.8	6,397	52.3	476	52.9	5,458	48.6
Private hospital	113	13.8	1,534	12.5	76	8.4	1,206	10.7
Outpatient clinic	1	0.1	53	0.4	6	0.7	26	0.2
General medical practitioner	5	0.6	386	3.2	164	18.2	1,523	13.6
Specialist medical practitioner	2	0.2	605	4.9	18	2.0	384	3.4
Community-based palliative care agency	276	33.7	2,717	22.2	32	3.6	327	2.9
Community-based service	2	0.2	54	0.4	16	1.8	168	1.5
Residential aged care facility	1	0.1	99	0.8	19	2.1	927	8.3
Self, carer(s), family or friends	6	0.7	156	1.3	65	7.2	371	3.3
Other	2	0.2	163	1.3	20	2.2	302	2.7
Not stated/inadequately described	11	1.3	60	0.5	8	0.9	533	4.7
Total	***819***	***100.0***	***12,224***	***100.0***	***900***	***100.0***	***11,225***	***100.0***

Table 16 provides a summary of the time between referral to first contact by setting of care. The time from referral to first contact is calculated as the time from the date of referral received to either the date of first contact (if provided) or the episode start date.

Table 16 Referral to first contact by episode setting

Time (in days)	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Same day or following day	692	84.5	11,383	93.1	641	71.4	5,932	52.9
2-7 days	107	13.1	716	5.9	209	23.3	3,711	33.1
8-14 days	14	1.7	61	0.5	30	3.3	883	7.9
Greater than 14 days	6	0.7	61	0.5	18	2.0	697	6.2
Average	1.5	na	1.2	na	2.0	na	2.8	na
Median	1	na	1	na	1	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Table 17 gives a summary of the length of episode for patients in South Australia and nationally. Table 18 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 17 Length of episode (in days) summary by setting

Length of episode	Inpatient		Community	
	SA	All Services	SA	All Services
Average length of episode	11.3	10.6	42.3	35.8
Median length of episode	7.0	6.0	32.0	24.0

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 18 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Same day	39	4.8	681	5.7	24	2.9	799	8.0
1-2 days	162	20.1	2,304	19.1	39	4.8	597	6.0
3-4 days	106	13.2	1,777	14.8	36	4.4	501	5.0
5-7 days	139	17.2	2,044	17.0	50	6.1	745	7.5
8-14 days	160	19.9	2,586	21.5	108	13.2	1,234	12.3
15-21 days	86	10.7	1,106	9.2	76	9.3	906	9.1
22-30 days	53	6.6	729	6.1	71	8.7	871	8.7
31-60 days	48	6.0	659	5.5	155	18.9	1,736	17.4
61-90 days	7	0.9	106	0.9	78	9.5	834	8.3
Greater than 90 days	6	0.7	50	0.4	182	22.2	1,776	17.8
Total	***806***	***100.0***	***12,042***	***100.0***	***819***	***100.0***	***9,999***	***100.0***

Note: Only episodes ending during the reporting period are included.

Table 19 How episodes start – inpatient setting

Episode start mode	SA		All Services	
	N	%	N	%
Admitted from community*	574	70.1	7,522	61.5
Admitted from another hospital	160	19.5	3,088	25.3
Admitted from acute care in another ward	73	8.9	1,343	11.0
Change from acute care to palliative care – same ward	3	0.4	173	1.4
Other**	9	1.1	92	0.8
Not stated/inadequately described	0	0.0	6	0.0
Total	***819***	***100.0***	***12,224***	***100.0***

* includes: admitted from usual accommodation, admitted from other than usual accommodation

** includes: change of sub-acute/non-acute care type and other categories

Table 20 How episodes end – inpatient setting

Episode end mode	SA		All Services	
	N	%	N	%
Discharged to community*	243	30.1	4,331	36.0
Discharged to another hospital	55	6.8	877	7.3
Death	493	61.2	6,507	54.0
Change from palliative care to acute care**	5	0.6	74	0.6
Change in sub-acute care type	0	0.0	38	0.3
End of consultative episode – inpatient episode ongoing	6	0.7	98	0.8
Other	3	0.4	111	0.9
Not stated/inadequately described	1	0.1	6	0.0
Total	***806***	***100.0***	***12,042***	***100.0***

Note: Only episodes ending during the reporting period are included.

* includes: discharged to usual accommodation, discharged to other than usual accommodation

** includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward

Table 21 How episodes start – community setting

Episode start mode	SA		All Services	
	N	%	N	%
Admitted from inpatient palliative care	159	17.7	4,137	36.9
Other*	739	82.1	7,035	62.7
Not stated/inadequately described	2	0.2	53	0.5
Total	***900***	***100.0***	***11,225***	***100.0***

*includes: patient was not transferred from being an overnight patient

Table 22 How episodes end – community setting

Episode end mode	SA		All Services	
	N	%	N	%
Admitted for inpatient palliative care	220	26.9	2,792	27.9
Admitted for inpatient acute care	302	36.9	2,677	26.8
Admitted to another palliative care service	9	1.1	133	1.3
Admitted to primary health care	47	5.7	611	6.1
Discharged/case closure	26	3.2	1,065	10.7
Death	201	24.5	2,569	25.7
Other	11	1.3	144	1.4
Not stated/inadequately described	3	0.4	8	0.1
Total	***819***	***100.0***	***9,999***	***100.0***

Note: Only episodes ending during the reporting period are included.

3.3 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix D for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

Table 23 Number of phases by phase type and setting

Phase type	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Stable	397	24.6	7,330	25.8	663	48.0	9,334	37.2
Unstable	247	15.3	6,544	23.0	159	11.5	3,180	12.7
Deteriorating	615	38.2	8,978	31.6	456	33.0	10,424	41.6
Terminal	352	21.8	5,557	19.6	102	7.4	2,120	8.5
Total	***1,611***	***100.0***	***28,409***	***100.0***	***1,380***	***100.0***	***25,058***	***100.0***

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 24 Average phase length (in days) by phase type and setting

Phase type	Inpatient		Community	
	SA	All Services	SA	All Services
Stable	8.2	6.9	29.2	19.8
Unstable	2.2	2.3	4.4	4.4
Deteriorating	7.2	5.5	17.4	12.7
Terminal	2.2	2.1	4.4	3.0

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

Table 25 presents information relating to the manner in which stable phases ended, both for South Australian services and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 15 summarises the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression. The phase progression information is derived by PCOC.

Similar information is presented for the unstable (Table 26, Figure 16), deteriorating (Table 27, Figure 17) and terminal (Table 28, Figure 18) phases on the following pages.

Table 25 How stable phases end – by setting

How stable phases end	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	194	48.9	3,681	50.2	294	44.3	6,076	65.1
Discharge/case closure	183	46.1	3,539	48.3	306	46.2	2,972	31.8
Died	18	4.5	103	1.4	36	5.4	247	2.6
Not stated/inadequately described	2	0.5	7	0.1	27	4.1	39	0.4
Total	***397***	***100.0***	***7,330***	***100.0***	***663***	***100.0***	***9,334***	***100.0***

Figure 15 Stable phase progression

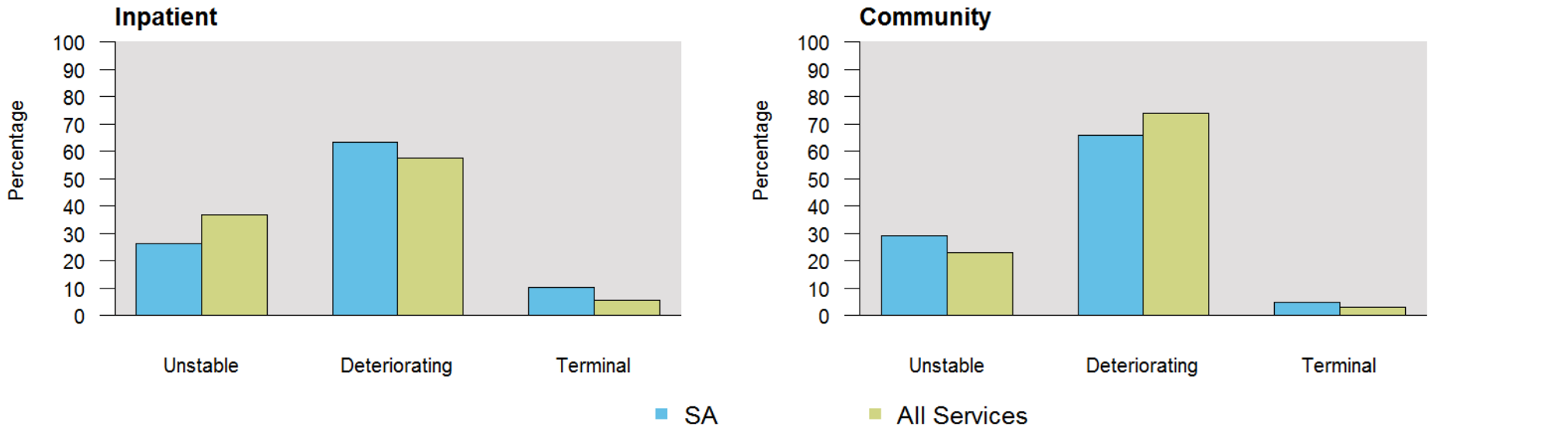


Table 26 How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	222	89.9	6,022	92.0	94	59.1	2,147	67.5
Discharge/case closure	13	5.3	367	5.6	59	37.1	963	30.3
Died	12	4.9	148	2.3	1	0.6	63	2.0
Not stated/inadequately described	0	0.0	7	0.1	5	3.1	7	0.2
Total	***247***	***100.0***	***6,544***	***100.0***	***159***	***100.0***	***3,180***	***100.0***

Figure 16 Unstable phase progression

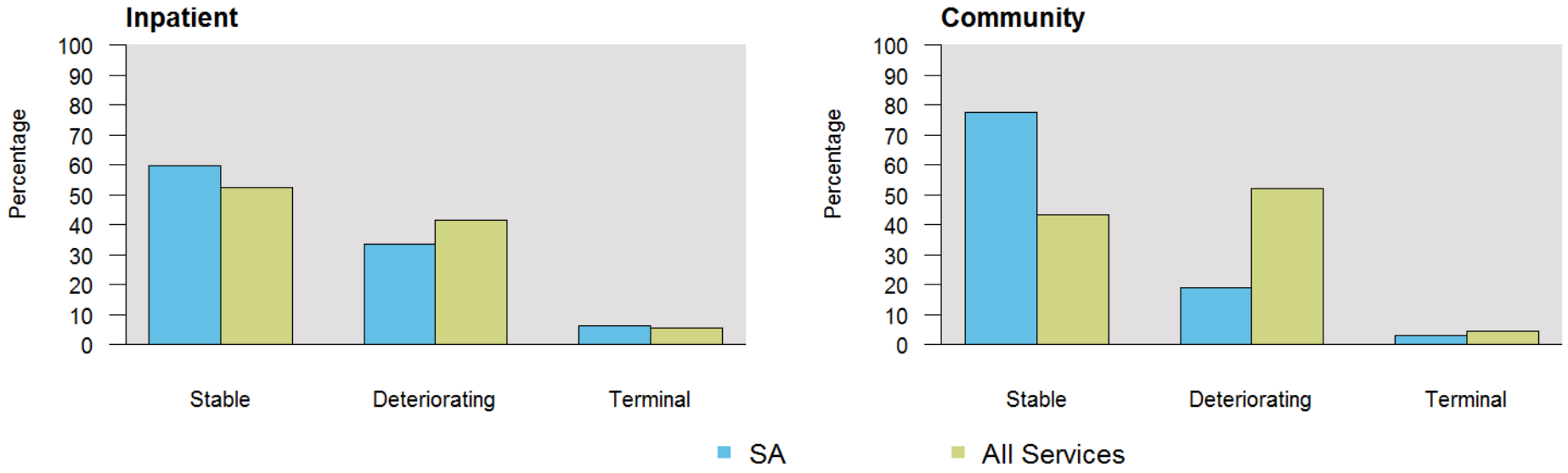


Table 27 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	374	60.8	6,444	71.8	170	37.3	6,442	61.8
Discharge/case closure	112	18.2	1,501	16.7	194	42.5	3,209	30.8
Died	126	20.5	1,027	11.4	81	17.8	762	7.3
Not stated/inadequately described	3	0.5	6	0.1	11	2.4	11	0.1
Total	***615***	***100.0***	***8,978***	***100.0***	***456***	***100.0***	***10,424***	***100.0***

Figure 17 Deteriorating phase progression

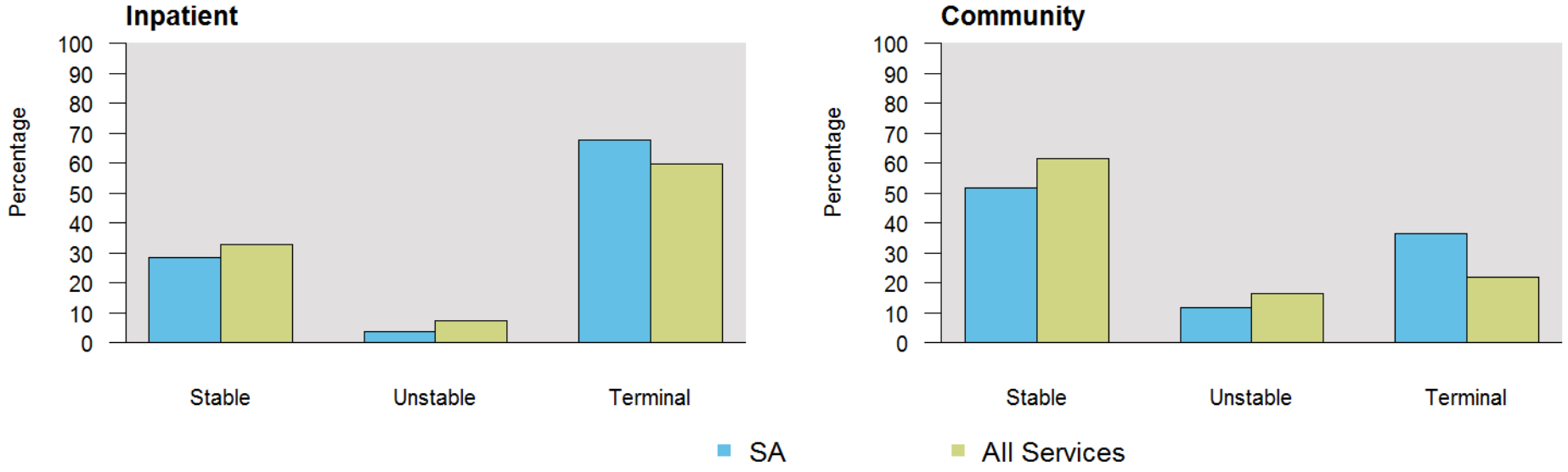
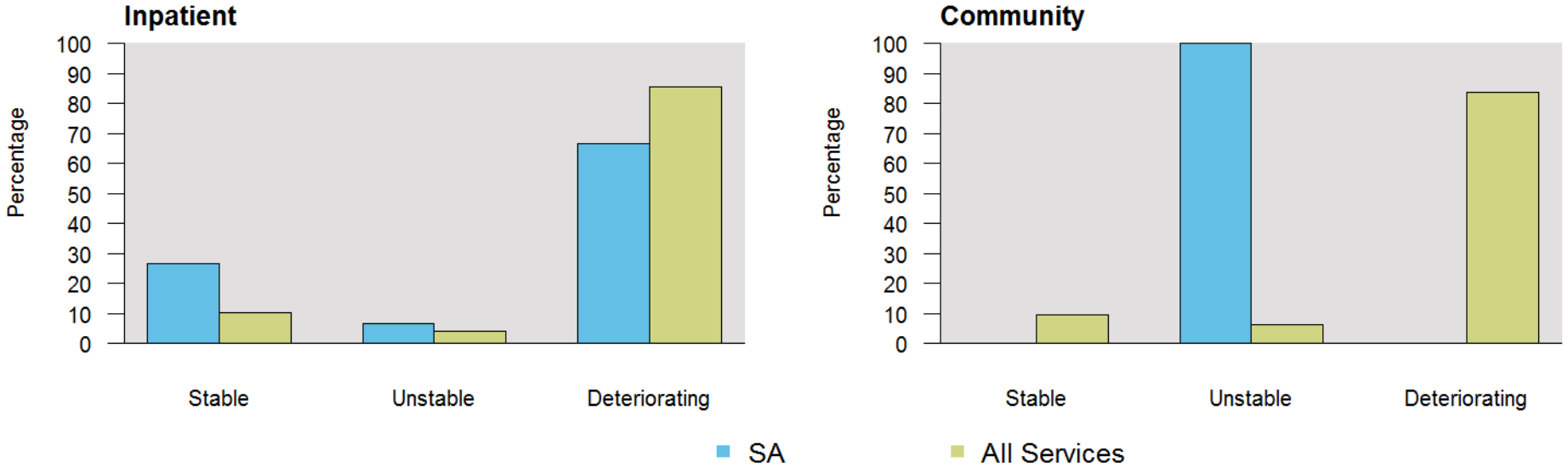


Table 28 How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	15	4.3	215	3.9	4	3.9	330	15.6
Discharge/case closure	1	0.3	106	1.9	14	13.7	241	11.4
Died	336	95.5	5,236	94.2	84	82.4	1,548	73.0
Not stated/inadequately described	0	0.0	0	0.0	0	0.0	1	0.0
Total	***352***	***100.0***	***5,557***	***100.0***	***102***	***100.0***	***2,120***	***100.0***

Figure 18 Terminal phase progression



The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological/spiritual and family/carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 29 and Table 30 show the percentage scores for the inpatient and community settings, respectively, for both South Australian services and nationally.

Table 29 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type		SA				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	35.5	43.7	15.6	5.1	48.8	37.6	11.0	2.5
	Other symptoms	19.6	47.1	26.2	7.1	25.8	51.9	19.1	3.3
	Psychological/spiritual	24.5	55.9	15.8	3.8	32.7	52.6	12.2	2.5
	Family/carer	27.0	50.0	16.5	6.5	40.6	43.1	12.8	3.4
Unstable	Pain	21.1	32.8	27.5	18.6	30.5	30.9	25.6	12.9
	Other symptoms	7.7	30.8	42.9	18.6	13.8	34.1	38.3	13.8
	Psychological/spiritual	9.3	48.2	33.2	9.3	23.8	44.1	24.8	7.4
	Family/carer	11.5	48.1	30.5	9.9	26.1	40.8	24.2	8.9
Deteriorating	Pain	31.6	41.7	19.1	7.5	38.4	35.9	19.7	5.9
	Other symptoms	13.0	53.1	27.5	6.4	15.3	40.8	33.5	10.4
	Psychological/spiritual	22.1	55.5	18.7	3.8	24.9	47.8	21.6	5.7
	Family/carer	27.0	45.4	21.2	6.3	27.6	41.6	23.0	7.8
Terminal	Pain	34.7	42.5	15.0	7.8	48.1	32.7	14.0	5.1
	Other symptoms	26.3	45.1	20.5	8.1	33.6	35.0	21.8	9.6
	Psychological/spiritual	44.9	39.7	12.2	3.2	51.1	31.8	12.5	4.6
	Family/carer	15.1	48.0	28.2	8.7	21.9	35.6	30.2	12.4

Table 30 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)

Phase type		SA				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	40.6	50.5	8.2	0.8	41.0	50.8	7.6	0.6
	Other symptoms	12.8	67.5	17.6	2.2	14.9	66.3	17.5	1.3
	Psychological/spiritual	33.0	53.7	11.6	1.7	30.2	58.5	10.2	1.1
	Family/carer	27.3	51.8	17.5	3.3	31.1	53.6	13.5	1.7
Unstable	Pain	24.5	30.3	27.7	17.4	18.3	28.7	33.6	19.4
	Other symptoms	7.6	26.8	39.5	26.1	5.4	28.0	48.4	18.3
	Psychological/spiritual	11.6	36.8	35.5	16.1	12.1	45.6	34.4	7.9
	Family/carer	8.1	34.2	37.6	20.1	14.1	34.8	39.3	11.8
Deteriorating	Pain	25.8	48.4	21.8	4.0	28.4	49.3	19.5	2.8
	Other symptoms	4.9	41.3	41.8	12.0	7.0	48.7	39.2	5.1
	Psychological/spiritual	14.9	54.8	24.1	6.2	18.4	58.0	20.8	2.9
	Family/carer	11.9	42.8	35.9	9.4	19.1	47.9	28.5	4.5
Terminal	Pain	33.7	48.0	16.3	2.0	35.7	44.4	15.8	4.1
	Other symptoms	24.5	46.9	15.3	13.3	20.9	40.9	29.6	8.6
	Psychological/spiritual	45.9	40.8	10.2	3.1	40.0	42.0	15.0	3.1
	Family/carer	11.2	36.7	34.7	17.3	12.6	40.1	36.8	10.5

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no problems to 10 - worst possible problems. The SAS reports on seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 31 and Table 32 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Additional information on the SAS profile by phase can be found in Appendix B.

Table 31 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type		SA				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	56.9	27.3	14.4	1.4	67.8	18.1	11.5	2.6
	Appetite problems	46.0	30.5	21.1	2.5	55.0	23.3	17.7	4.0
	Nausea	77.6	14.1	7.2	1.1	79.7	13.2	6.0	1.0
	Bowel problems	51.8	23.5	18.8	5.8	61.8	21.7	13.5	3.1
	Breathing problems	56.0	24.1	15.8	4.2	64.8	18.2	13.6	3.4
	Fatigue	17.2	28.0	47.1	7.8	27.3	25.0	38.4	9.3
	Pain	29.9	43.8	23.5	2.8	46.3	31.9	18.9	3.0
Unstable	Difficulty sleeping	43.1	24.6	22.8	9.5	57.6	17.5	18.7	6.1
	Appetite problems	36.9	23.2	32.6	7.3	41.8	22.4	25.8	10.0
	Nausea	63.7	17.5	13.2	5.6	68.3	14.3	12.2	5.3
	Bowel problems	40.2	27.8	25.6	6.4	50.9	21.2	20.7	7.3
	Breathing problems	42.7	24.8	21.4	11.1	55.2	17.2	18.6	8.9
	Fatigue	16.7	14.6	54.9	13.7	21.2	17.1	43.4	18.3
	Pain	20.5	29.9	38.0	11.5	30.9	24.6	31.8	12.7
Deteriorating	Difficulty sleeping	59.0	23.1	15.1	2.9	67.5	15.3	14.0	3.2
	Appetite problems	47.3	24.1	22.0	6.6	50.9	19.0	22.1	7.9
	Nausea	73.7	17.7	6.0	2.7	76.2	12.3	9.2	2.3
	Bowel problems	54.1	24.6	15.9	5.4	59.5	20.3	15.9	4.3
	Breathing problems	50.5	22.2	21.8	5.5	55.5	18.1	18.6	7.8
	Fatigue	19.5	20.9	46.8	12.7	24.8	14.7	41.0	19.5
	Pain	23.0	41.2	28.8	7.0	38.2	29.1	26.7	6.0
Terminal	Difficulty sleeping	87.9	7.2	3.9	1.0	90.0	4.8	4.2	1.1
	Appetite problems	90.6	4.2	3.3	2.0	87.8	3.7	5.0	3.5
	Nausea	96.7	1.6	1.0	0.7	93.0	3.7	2.4	0.9
	Bowel problems	87.9	4.9	4.9	2.3	84.4	7.7	5.8	2.2
	Breathing problems	61.4	18.3	15.0	5.2	67.6	12.4	13.4	6.6
	Fatigue	67.5	6.9	13.1	12.5	71.0	4.7	12.0	12.3
	Pain	33.6	41.0	19.5	5.9	56.3	22.4	16.9	4.3

Table 32 Profile of SAS scores at beginning of phase by phase type –community setting (percentages)

Phase type		SA				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	55.3	29.2	14.1	1.4	63.5	25.9	9.6	0.9
	Appetite problems	39.1	30.5	27.0	3.4	48.4	33.3	16.4	1.9
	Nausea	72.2	22.3	4.9	0.6	80.5	15.9	3.3	0.3
	Bowel problems	55.5	32.5	10.4	1.7	67.7	24.3	7.1	0.9
	Breathing problems	46.9	30.5	20.1	2.5	54.4	30.2	13.6	1.7
	Fatigue	14.4	27.1	47.6	10.9	15.6	34.3	44.6	5.5
	Pain	38.3	41.8	17.9	2.0	44.3	41.8	12.8	1.1
Unstable	Difficulty sleeping	45.7	20.5	26.5	7.3	44.7	25.6	23.8	5.9
	Appetite problems	32.2	27.0	35.5	5.3	34.9	26.4	29.5	9.2
	Nausea	61.4	20.9	13.1	4.6	61.0	17.6	15.1	6.2
	Bowel problems	41.8	28.8	17.6	11.8	52.9	26.4	15.4	5.3
	Breathing problems	55.6	17.0	21.6	5.9	47.2	26.2	20.0	6.6
	Fatigue	15.1	19.7	46.1	19.1	10.0	18.2	52.6	19.2
	Pain	26.8	23.5	26.8	22.9	20.3	24.1	35.9	19.7
Deteriorating	Difficulty sleeping	51.9	26.1	17.7	4.3	57.0	27.5	13.5	2.0
	Appetite problems	32.0	24.5	34.7	8.8	39.0	30.4	25.7	5.0
	Nausea	67.8	19.7	10.9	1.6	73.0	18.7	7.3	1.1
	Bowel problems	45.4	32.4	17.5	4.8	61.7	25.9	10.6	1.7
	Breathing problems	46.9	23.8	22.2	7.0	47.6	30.7	18.7	3.1
	Fatigue	10.0	14.3	51.9	23.8	10.6	22.3	54.5	12.7
	Pain	25.1	40.3	30.1	4.5	32.3	40.9	23.2	3.6
Terminal	Difficulty sleeping	78.7	11.7	7.4	2.1	75.7	13.6	8.4	2.2
	Appetite problems	78.7	8.5	5.3	7.4	78.1	6.6	7.3	8.0
	Nausea	88.3	9.6	1.1	1.1	85.0	8.9	4.9	1.2
	Bowel problems	78.7	9.6	7.4	4.3	74.1	15.7	8.4	1.8
	Breathing problems	57.4	24.5	14.9	3.2	55.5	22.8	17.0	4.6
	Fatigue	53.2	6.4	13.8	26.6	57.4	5.0	13.7	23.9
	Pain	36.2	38.3	23.4	2.1	40.9	35.5	19.6	4.0

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 33 shows the data for the AKPS at phase start.

Table 33 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment	Inpatient				Community			
	SA		All Services		SA		All Services	
	N	%	N	%	N	%	N	%
10 - Comatose or barely rousable	194	12.0	2,907	10.2	36	2.6	822	3.3
20 - Totally bedfast and requiring extensive nursing care	386	24.0	6,243	22.0	108	7.8	2,428	9.7
30 - Almost completely bedfast	223	13.8	3,860	13.6	82	5.9	1,682	6.7
40 - In bed more than 50% of the time	327	20.3	5,151	18.1	179	13.0	3,161	12.6
50 - Requires considerable assistance	297	18.4	4,855	17.1	377	27.3	5,864	23.4
60 - Requires occasional assistance	138	8.6	2,947	10.4	360	26.1	6,317	25.2
70 - Cares for self	18	1.1	706	2.5	151	10.9	3,322	13.3
80 - Normal activity with effort	6	0.4	215	0.8	50	3.6	699	2.8
90 - Able to carry on normal activity; minor signs or symptoms	3	0.2	56	0.2	15	1.1	155	0.6
100 - Normal; no complaints; no evidence of disease	0	0.0	1	0.0	0	0.0	13	0.1
Not stated/inadequately described	19	1.2	1,468	5.2	22	1.6	595	2.4
Total	***1,611***	***100.0***	***28,409***	***100.0***	***1,380***	***100.0***	***25,058***	***100.0***

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Figure 19 and Figure 20 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients and community patients. The total score on the RUG-ADL ranges from a minimum of 4 (lowest level of functional dependency) to a maximum of 18 (highest level of functional dependency).

AKPS & RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements.

Figure 19 Total RUG-ADL at beginning of phase by phase type – inpatient setting

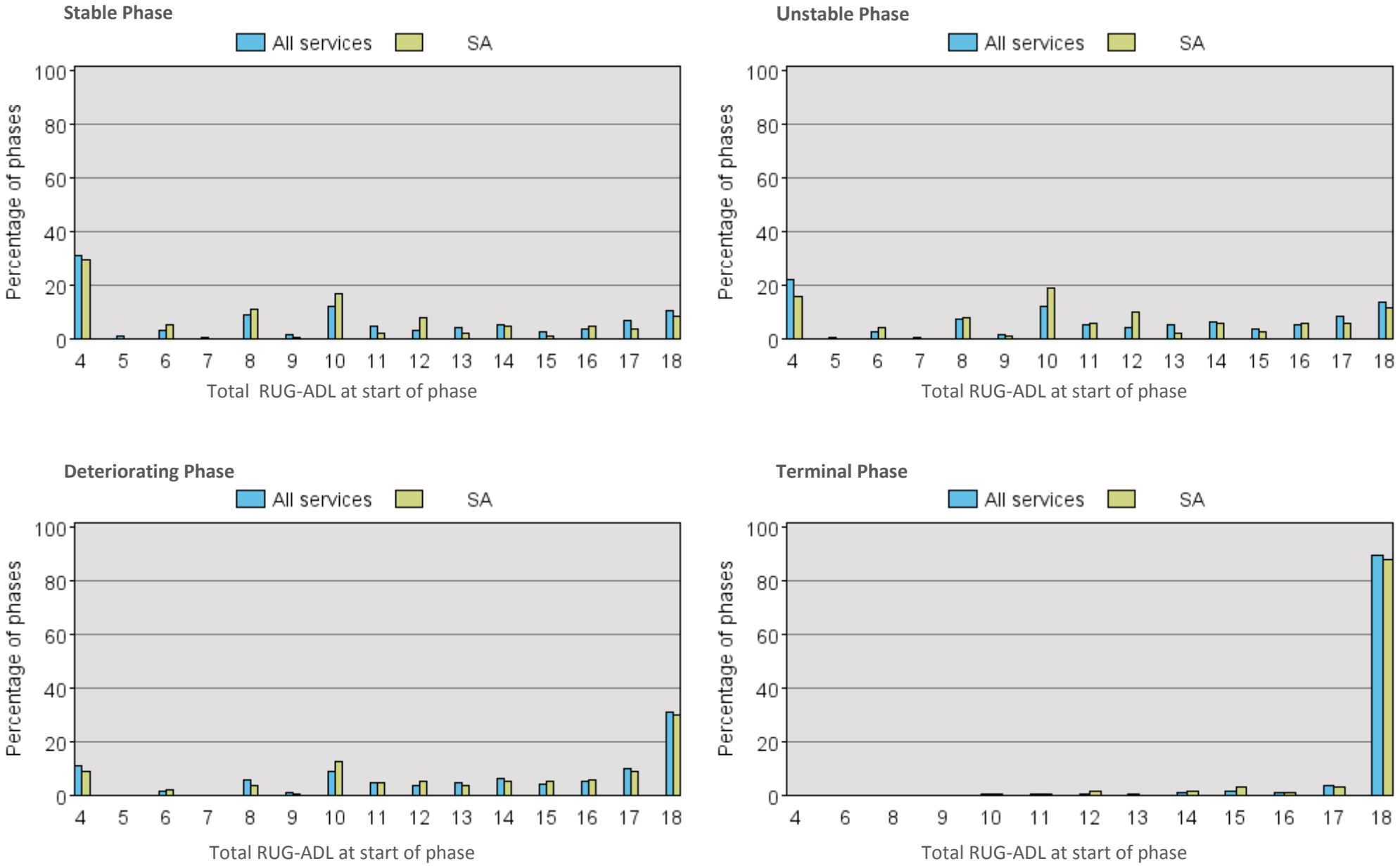
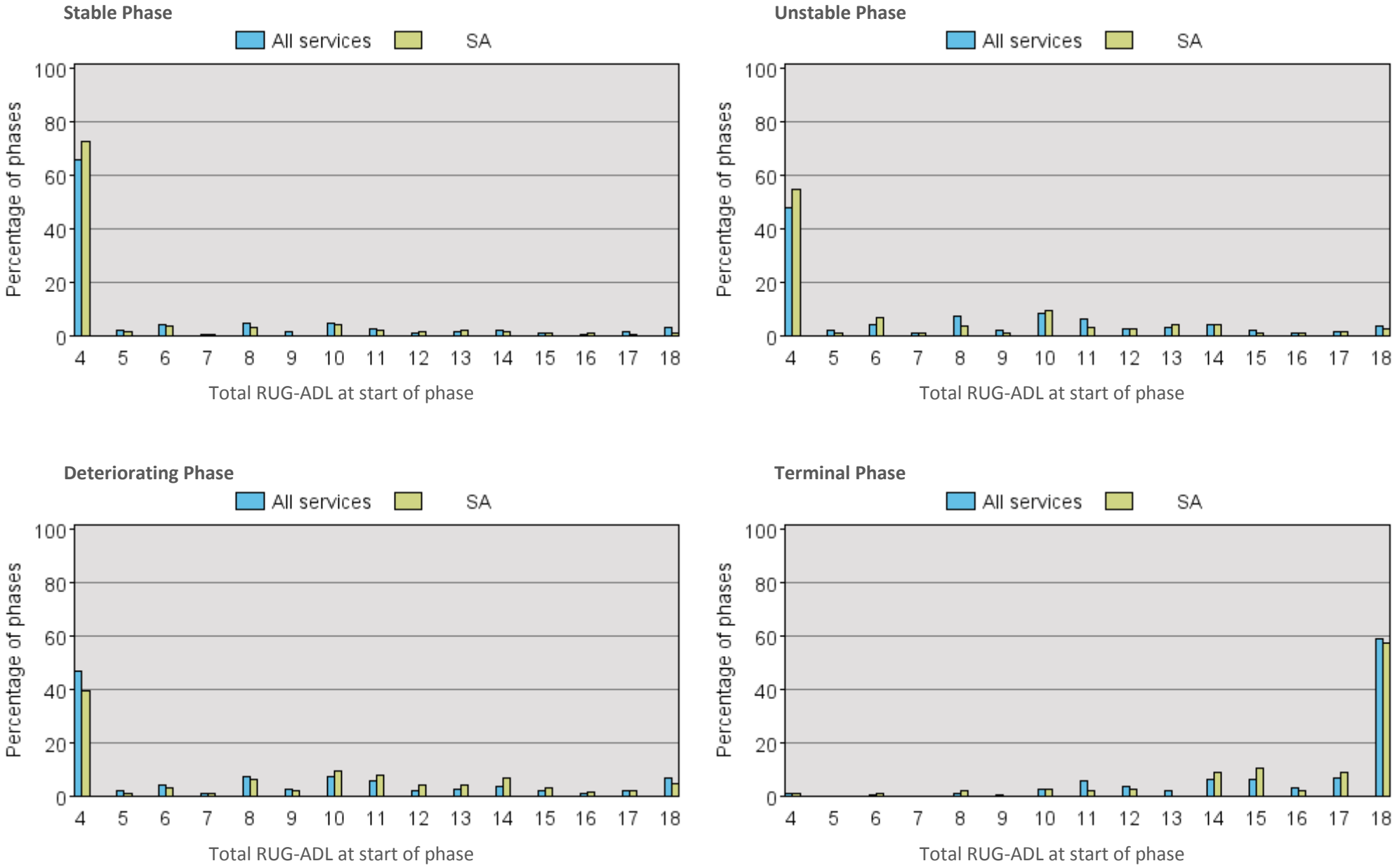


Figure 20 Total RUG-ADL at beginning of phase by phase type – community setting



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 18,310 patients who between them had 23,449 episodes of care and 53,467 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix B contains a more detailed explanation of this process). Table 34 shows the number of patients, episodes and phases included in this report – both for South Australian services and nationally.

A consequence of the data scoping method is that it is likely that not all phases related to a particular episode are included in this report. Hence, the average number of phases per episode calculation shown in Table 34 may be an underestimate (due to episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

Table 34 Number and percentage of patients, episodes and phases by setting

	Inpatient		Community		Total	
	SA	All Services	SA	All Services	SA	All Services
Number of patients*	701	10,311	745	8,963	1,313	18,310
Number of episodes	819	12,224	900	11,225	1,719	23,449
Number of phases**	1,611	28,409	1,380	25,058	2,991	53,467
Percentage of patients*	53.4	56.3	56.7	49.0	100	100
Percentage of episodes	47.6	52.1	52.4	47.9	100	100
Percentage of phases	53.9	53.1	46.1	46.9	100	100
Average number of phases per episode***	2.0	2.3	1.4	2.0	1.7	2.2

* Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.
** Bereavement phases are excluded from this count.
*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 35 shows the number of completed episodes and phases by setting for each month in the current reporting period for South Australian services. This table allows a service to identify any change in patient numbers during the reporting period.

Table 35 Number of completed episodes and phases by month and setting

		Jul	Aug	Sep	Oct	Nov	Dec
Inpatient	No. of completed episodes	117	151	139	139	131	129
	No. of completed phases	246	288	281	266	282	248
Community	No. of completed episodes	122	157	122	129	142	147
	No. of completed phases	228	247	203	215	239	248

A2 Data item completion

As shown in Table 36, Table 37 and Table 38 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

Table 36 Item completion (per cent complete) - patient level

Data item	SA	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	95.0	98.0
Country of birth	94.4	98.5
Preferred language	100.0	100.0
Primary diagnosis	100.0	99.7

Note: This table is not split by setting to be consistent with the patient level analysis throughout this report.

Table 37 Item completion by setting (per cent complete) - episode level

Data item	Inpatient		Community		Total	
	SA	All Services	SA	All Services	SA	All Services
Date of first contact	100.0	100.0	99.8	100.0	99.9	100.0
Referral date	100.0	100.0	99.8	100.0	99.9	100.0
Referral source	98.7	99.5	99.1	95.3	98.9	97.5
Date ready for care	100.0	94.7	100.0	100.0	100.0	97.2
Mode of episode start	100.0	100.0	99.8	99.5	99.9	99.7
Accommodation at episode start	99.1	99.9	99.8	96.3	99.5	97.7
Episode end date*	99.8	99.8	93.9	92.2	96.7	96.2
Mode of episode end	99.9	100.0	99.6	99.9	99.8	99.9
Accommodation at episode end	93.1	98.6	95.3	91.8	93.7	96.5
Place of death	na	na	98.6	96.6	98.6	96.6

* Episode end date item completion may be affected by open episodes.

Table 38 Item completion by setting (per cent complete) - phase level

Data item	Sub-Category	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
	(where applicable)	SA	All Services	SA	All Services	SA	All Services	SA	All Services	SA	All Services	SA	All Services
RUG-ADL	Bed mobility	99.8	99.7	99.7	97.4	99.7	98.6	76.4	92.3	44.0	63.2	55.3	75.7
	Toileting	99.7	99.7	99.7	97.3	99.7	98.6	76.4	92.3	43.8	63.2	55.2	75.6
	Transfers	99.7	99.7	99.7	96.7	99.7	98.3	76.4	92.3	43.8	63.2	55.2	75.6
	Eating	98.7	99.5	99.7	95.6	99.2	97.7	76.4	92.3	43.6	62.8	55.1	75.4
PCPSS	Pain	99.0	97.8	97.9	97.5	98.5	97.6	76.1	91.1	42.1	62.9	54.0	75.0
	Other symptom	99.1	97.6	98.1	96.7	98.6	97.2	76.4	91.1	42.1	62.5	54.1	74.7
	Psychological/spiritual	99.0	99.4	97.8	97.2	98.5	98.4	76.4	92.2	41.9	62.8	54.0	75.4
	Family/carer	97.6	97.3	95.0	96.0	96.4	96.7	74.4	88.0	41.2	62.2	52.8	73.2
SAS	Difficulty sleeping	86.0	92.9	96.6	93.8	90.9	93.3	51.8	81.3	41.4	60.4	45.0	69.3
	Appetite problems	86.1	93.1	96.5	95.0	90.9	94.0	51.5	81.5	41.0	61.7	44.7	70.2
	Nausea	86.2	93.2	96.7	96.4	91.1	94.7	51.5	81.7	41.0	62.4	44.7	70.6
	Bowel problems	86.0	93.0	96.7	95.0	91.0	93.9	51.5	81.5	41.0	61.3	44.7	69.9
	Breathing problems	86.2	93.2	96.7	96.0	91.0	94.5	51.8	81.6	41.0	62.0	44.8	70.4
	Fatigue	86.0	93.2	96.5	96.1	90.9	94.5	51.8	81.6	41.0	62.3	44.8	70.5
	Pain	86.2	93.2	96.9	97.3	91.1	95.1	51.8	81.6	41.0	63.0	44.8	71.0
AKPS	-	98.8	94.8	98.4	97.6	98.6	96.1	75.4	89.7	43.8	63.2	54.9	74.5

Data item	Inpatient		Community		Total	
	SA	All Services	SA	All Services	SA	All Services
Phase End Reason	99.7	99.9	96.7	99.7	98.3	99.8

Appendix B Additional information on profile of SAS scores

Figure 21 Profile of SAS Score by symptom – inpatient setting

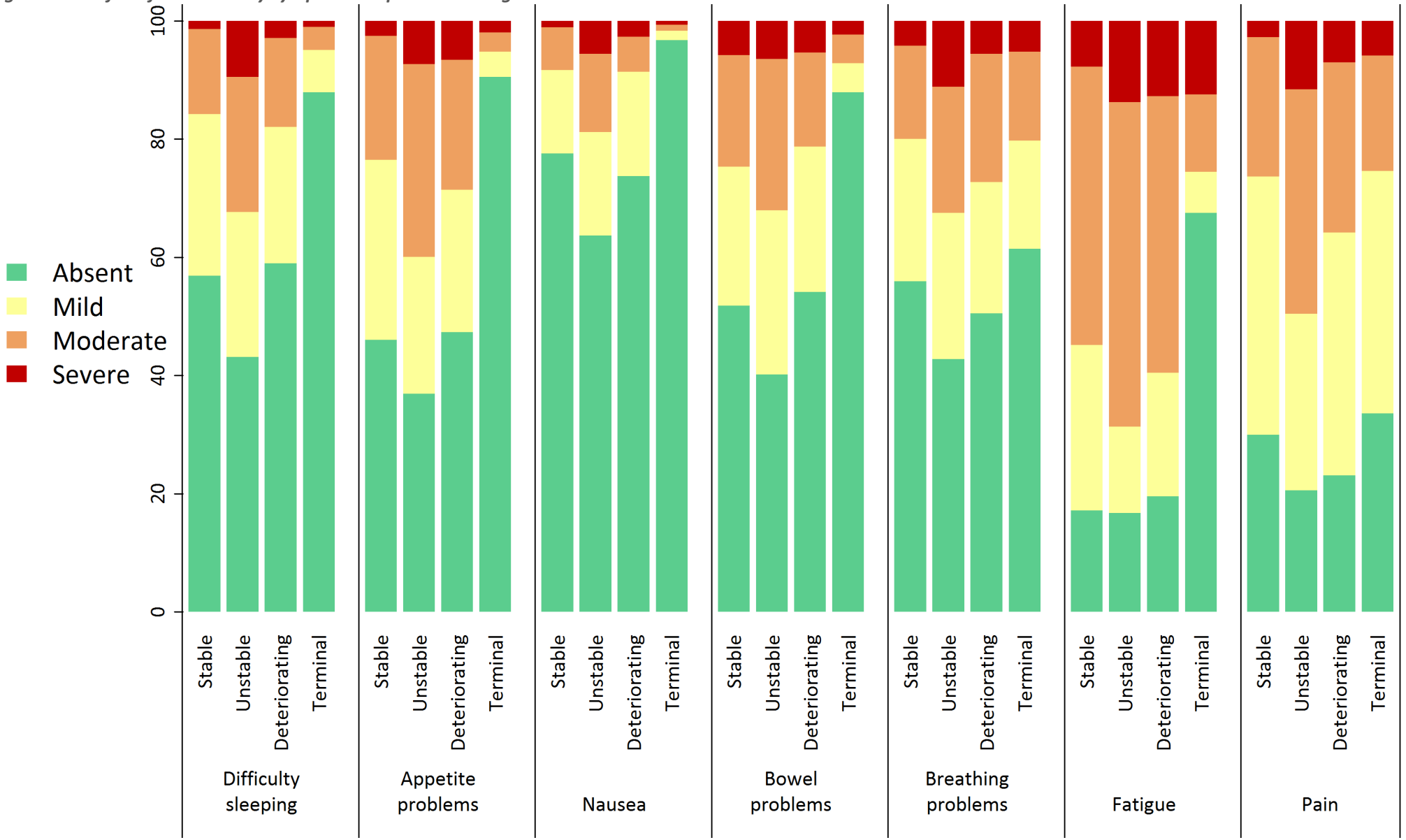
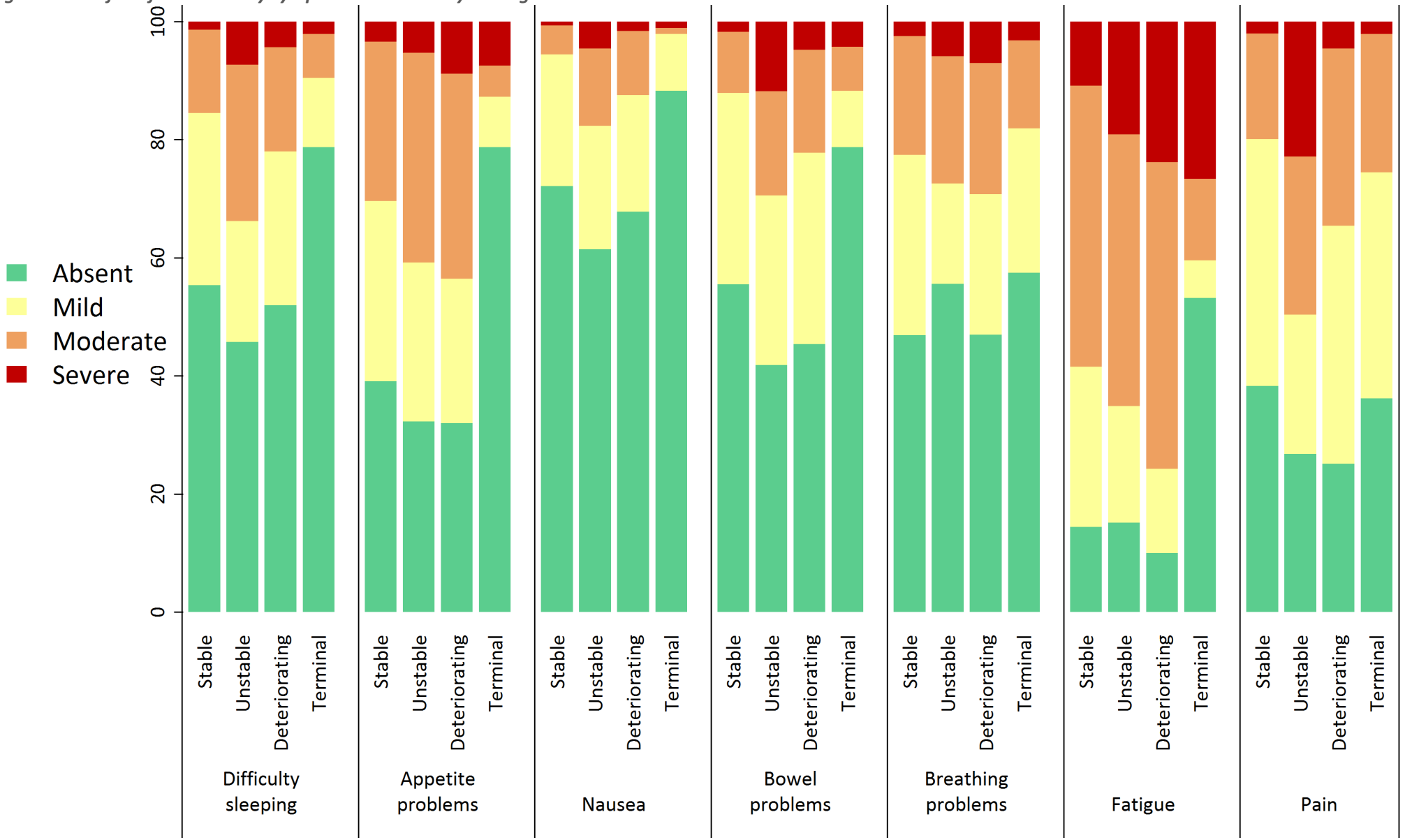


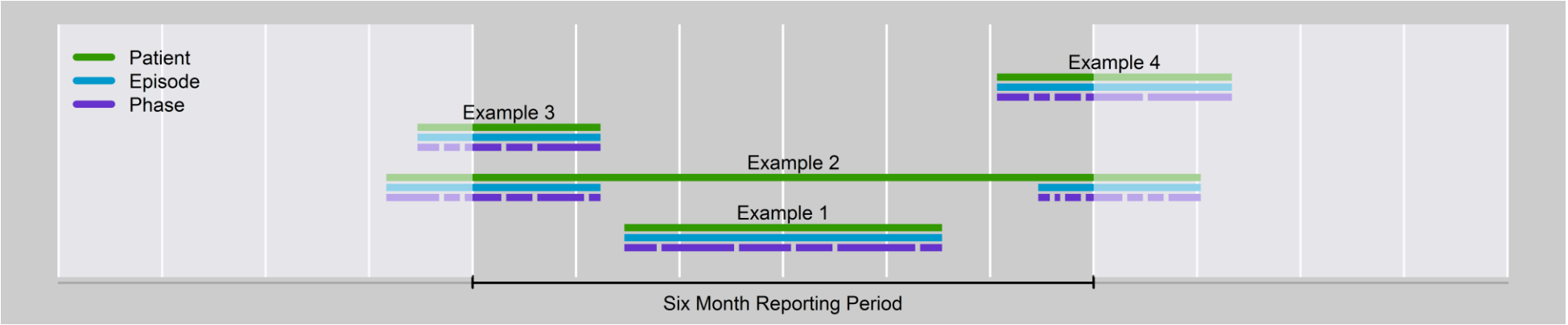
Figure 22 Profile of SAS Score by symptom – community setting



Appendix C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 23 below displays four examples to help visualize this process.

Figure 23 Diagram of the PCOC data scoping method



In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

In Example 3, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

Appendix D Palliative Care Phase definitions

START	END
1. Stable	
Patient problems and symptoms are adequately controlled by established plan of care **and** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care.
2. Unstable	
An urgent change in the plan of care or emergency treatment is required **because** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and/or** ▪ Family/ carers circumstances change suddenly impacting on patient care.	▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and/or** ▪ Death is likely within days (i.e. patient is now terminal).
3. Deteriorating	
The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and** ▪ Patient experiences a gradual worsening of existing problem **and/or** ▪ Patient experiences a new but anticipated problem **and/or** ▪ Family/carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and/or** ▪ Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
4. Terminal	
Death is likely within days.	▪ Patient dies **or** ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
5. Bereavement – post death support	
▪ The patient has died ▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record.	▪ Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

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Disclaimer PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.

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